

Patient and Public Involvement (PPI)

“No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights.” Dame Sally Davies, Chief Medical Officer, 2009. ***Patient and Public Involvement (PPI)*** volunteers contribute their expertise, helping to develop ideas, assisting with writing grant proposals, undertaking research and disseminating research findings. This leaflet provides a handy ‘top ten tips’ to PPI for AHPs.

Tip 1 - Working with the experts

PPI volunteers/contributors/partners often have great insight into their own, or their family member’s condition. Their understanding can prove to be invaluable throughout the research process. Think carefully about who you could invite to join your team as a PPI partner, considering the relevance of your research ideas, and who may be appropriate and able to advise you on your plans.

Tip 2 - Early PPI involvement

Plan PPI partnerships early, even before you have decided your research question; approaching PPI volunteers at an early stage helps ensure research ideas taken forward are feasible. Working informally with a few key individuals from the beginning may well save a great deal of work in the end. Explain your research in simple, accessible language which can be easily understood.

Tip 3 - Who to approach?

Consider who may like to be involved and join your team, perhaps someone with experience of the condition or similar personal characteristics to the people you are planning on researching. Approach people from a range of backgrounds and ethnicities to provide different opinions, highlighting aspects you may not have considered. Drafting a ‘person specification’ and advertising may be helpful.

Tip 4 - Where to seek volunteers

Consider approaching patients you have worked with before or established patient/service user/public groups in your area. For example, you could ask your local stroke club. There are online resources too you may like to use eg invoDIRECT www.invo.org.uk/communities/invodirect or People in Research www.peopleinresearch.org. Your local National Institute for Health Research (NIHR) Research Design Service may help too.

Tip 5 - Your research plan

Consider which aspects will benefit most from PPI involvement eg significance of the study from a patient/public perspective, writing lay summaries, participant information, recruitment strategies and acceptability of interventions/outcome measurements. Seek PPI advice regarding data collection, including development of interview schedules. Also, consider how PPI volunteers can be involved throughout the research process, including co-presentation/acknowledgement or co-authoring when disseminating findings.

Tip 6 – Training requirements

Consider what support and training requirements there may be for you, your team and the people you involve (PPI volunteers). Talk to people who have experience of working with PPI volunteers, or attend relevant courses. Be prepared to discuss research aspects in lay terms, providing a glossary if required. Consult the recommendations for learning and development for public involvement: www.invo.org.uk/wp-content/uploads/2016/03/FINAL-NIHR-LD-report-July-2015.pdf

Tip 7 – Consider finance issues

Volunteers should, at the very least, be reimbursed their expenses, or receive payment (if they choose) for their involvement (INVOLVE, www.invo.org.uk). Information about a benefits advice service for involvement is available here: www.invo.org.uk/resource-centre/benefits-advice-service. Consider paying travel/parking expenses in advance. Also remember refreshments/catering and venue hire costs, as well as training costs. Build PPI costs into grant applications.

Tip 8 - Research Design Service (RDS)

Contact your local RDS for support (www.rds.nihr.ac.uk). Consider applying for a Public Involvement fund Award (if offered), to support your public involvement during development of the research grant. You could also seek alternative funding from your institution to support PPI work. Money could be used to cover payment, travel expenses, venues, refreshments etc. enabling early PPI work.

Tip 9 - Document PPI involvement

Keep a record of PPI involvement (formal/informal). This is important to support your grant application. Be specific and as detailed as possible, stating exactly how PPI volunteers have informed the proposal and how they will be involved during the research process. Use of quotes can be very powerful and supportive. This information is also valuable for follow up research reports.

Tip 10 - Further guidance

Please refer to these resources for additional guidance and support

- RDS Handbook for Researchers - Patient and Public Involvement www.rds.nihr.ac.uk/latest-news/rds-patient-and-public-involvement-handbook
- INVOLVE Cost Calculator and Budgeting for Patient and Public Involvement www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator
- Guidance for writing plain English summaries www.invo.org.uk/makeitclear

- INVOLVE Public involvement in research: values and principles framework www.invo.org.uk/wp-content/uploads/2015/11/Values-and-Principles-framework-final-October-2015.pdf
- Going the Extra Mile: Final NIHR report and recommendations for public involvement 2015-25: www.nihr.ac.uk/documents/about-NIHR/NIHR-Publications/Extra%20Mile2.pdf

For contact details about your local hub and for further information about **cahpr** please visit our website www.cahpr.org.uk/cahpr

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